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Micro Interactions, Macro Harms: Some Thoughts on Improving Health Care for Transgender and Gender Nonbinary Folks

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For a variety of reasons, it's difficult to determine, with any accuracy, the number of trans and gender nonbinary folks living in the United States.[1] Data are difficult to obtain since neither the U.S. Census Bureau nor the Centers for Disease Control and Prevention (CDC) survey people's gender identity (Chalabai 2014). But even if they did, responses would likely be unreliable. Many members of these two groups are hesitant to answer such questions for fear of their safety, resulting discrimination, or because they disagree on the definition of what it means to be transgender (Chalabai 2014). It's also difficult to obtain accurate numbers on these groups since most medical forms still rely on a two-sex system of identification (male and female), do not ask about gender identity, and fail to provide the categories "transgender," "transman," and "transwoman." But even if medical forms did provide such options, many trans folks wouldn't check them since they identify as either male or female. The most recent study on this topic (as of September 2017) estimates that one in every 250 adults or almost one million Americans are transgender (Meerwijk and Sevelius 2017). However, it's likely that even this number is lower than the actual number of transgender individuals since many fear outing themselves as transgender for the reasons mentioned above.

Even trickier than obtaining an accurate number of transgender people is obtaining statistical data on people who are gender nonbinary since the category itself is so diverse, and also because, as with trans folks, there are no agencies that track this information (see Eckstrand et al. 2016 for a helpful discussion on this matter[2]). Moreover, few if any medical forms provide patients with options like "genderqueer," "agender," or "gender nonbinary." Like many trans folks, gender nonbinary folks also tend not to out themselves in public forums, on demographic forms, and, in particular, in medical contexts. In fact, many nonbinary folks choose to identify as either male or female

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within those contexts precisely to avoid mistreatment, discrimination, and other psychological harms (Harrison et al. 2012; Freeman 2017). Thus, we have no accurate numbers of how many people fall into this group either. Precision aside, it is the case that there are a large number of people who are either transgender or gender nonbinary, and all of them both require and have a right to access high quality health care. Yet, for a variety of reasons, it is the case that many members of these groups do not receive such care.

According to the 2015 U.S. Transgender Survey (Veale et al. 2015), the largest survey of its kind with responses from over 28,000 participants, transgender individuals are systematically discriminated against in health care settings. According to the survey, 23 percent avoid seeking necessary health care for fear of negative interactions with health care providers, and 33 percent are unable to afford health care at all. In Canada, where health care is more accessible than in the United States, 20 percent of transgender people surveyed have avoided visiting the emergency department due to fear of negative consequences from providers (Bauer et al. 2009[3]). For those who were able to access health care services, they reported negative interactions like harassment; others were refused services altogether on account of their being trans. In a more recent survey of transgender youth in Canada, though 70 percent of participants had a family doctor, only 15 percent of them felt "very comfortable" talking with their doctors about their trans status and trans-specific health care needs (Veale et al. 2015, 33). It is also quite common for transgender youth to use walk-in clinics for their health care needs. As one seventeen-year-old participant in British Columbia Canada noted:

> I feel uncomfortable [with walk-in clinics] because almost consistently, the older doctors I see looking to get a refill on my [hormone prescription] don't understand what being trans is, and will treat me with skepticism and concern, sometimes refusing to give pills at all because they were never trained in trans issues. (32)

In this commentary, I'd like to share and reflect upon some of the findings from a series of focus groups I conducted in the fall of 2017 with trans and gender nonbinary folks living in Louisville, Kentucky. The topic of the discussions was improving the general health and health care for members of these groups. This research was part of a larger project on the topic of microaggressions in clinical medicine on which I'm working, My aim for the focus groups was to learn more about the specific harms that trans and gender nonbinary folks suffer in the context of clinical medicine. The sample size for the focus groups was quite small (seven people ages 19 to 36), and unfortunately, though not surprisingly, it was not racially diverse.[4] It would be the topic of another commentary to discuss the difficulties of doing empirically informed work with no training in the area, and specifically of recruiting members of these groups as a white, cisgender woman. Nevertheless, the benefit of the

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small group size was that it allowed for much more in-depth and personal discussions than would have been possible with a larger group. Participants opened up in more ways than I could have imagined, and I am forever grateful for this.

I asked participants of each focus group to address two issues; first, to discuss a negative experience they'd had in a health care setting; and second, to discuss a positive experience they'd had in a health care setting. For the purposes of this commentary, I will focus only on the former. More specifically, I want to reflect upon one important finding. I've chosen to do so not only because of its relevance beyond the context of health care—all of us ought to take note of this problem, be mindful of its harmful consequences, and do what we can (personally and institutionally) to help resolve it—but also for the following reason. The harm that I noticed might seem so small and inconsequential to those of us who are not transgender or gender nonbinary and, in particular, to those who don't know a whole lot about what it's like to live as a transgender or gender nonbinary individual in a cisnormative society. In fact, the harm on which I'd like to focus might seem so small so as to fly completely under the radar. However, this seemingly micro harm (from one perspective) that is often, though not always, committed unintentionally, is anything but micro for its victims. For those who experience it, this harm has devastatingly macro consequences, both psychological and physical, in the immediate present and in the long term.

As one with any familiarity with trans health would imagine, the topics covered in response to the first question included lack of access to care and the resulting problems; the problem of insurance not covering necessary medical care (postsurgery, postgender-marker change, or postchange in legal sex status[5]); the lack of privacy in hospital rooms; the danger of binding for extended periods[6] and, in particular, of binding in health care settings; the difficulty and fear of being touched by health care providers for those who have struggled with their embodiment, specifically to present as their gender identity;[7] the problem of consent (to be touched); and a general lack of trust in the medical profession and, as a result, of avoiding health care contexts altogether. Each of these issues is of serious concern, though none was particularly surprising given the lack of robust training on them in medical and nursing schools.[8] Moreover, each of these issues is in line with the research done on this subject (see, for example, Bauer et al. 2009; Grant et al. 2010; Harrison et al. 2012).

However, what stood out most to me in the responses to that first question—something that was common to all participants—and what for many caused the most harm in medical settings, was something that happened well before the participants even encountered any physicians, nurses, or nurse practitioners. It was, in fact, nothing strictly *medical* at all; yet, it has severe, possibly even fatal health consequences. The most serious harm that all of the

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participants experienced in a medical setting resulted from the various dangers found in the waiting room. Let me explain.

It was consistently the case that within medical settings where participants felt most unsafe and suffered the most harm was in their encounters with administrative assistants and support staff. Each participant experienced being deadnamed, mis-gendered, and outed in the common space of a hospital or doctor's waiting room.[9] Such an experience was enough for several participants to forego any further medical care no matter what. If they did seek medical care, both pre- and postappointment, they suffered extreme anxiety and psychological fallout about being deadnamed, misgendered, and outed.

Jasper,[10] a thirty-six-year-old trans man, relayed the following experience that he had in his doctor's waiting room:

> I went to my [primary care physician], who is amazing; however, the staff was where the pitfalls happened. Instead of just coming to the waiting room and saying my last name, they used "Ms." And there was actually another person with the same last name—a female—in the room, so I just hung out and was like, "Well, maybe they're talking to her." And she didn't move, and so then it got real awkward, and then they said my birth name and my last name. And then I was like, now I gotta, you know, go, and, I'm sure nobody even noticed, but me.... And when I walked back, I said, "It is Mr. [last name redacted for anonymity]; I identify as male and use male pronouns [so] please use my preferred name, which is Jasper." And she said, "Oh, well, there's no note in here." There wasn't an immediate apology or anything. It was, "Oh, there's no note in here," but there *was* an actual note stating my preferred name. When my doctor came in, she apologized profusely and showed me that there was a note...which I knew because I had been in there a couple of other times and everyone...used male pronouns and called me by me preferred name. So, um, that was, that was a sticky one.

In his account, in addition to the deadnaming, misgendering, and being outed in the waiting room, Jasper also experienced gaslighting,[11] being lied to, and dehumanization. All of these experiences are harmful. They are harmful on their own; they are even more harmful when compiled; but they are triply harmful when they occur in the context of health care, where, as a patient, one is already vulnerable and seeking to be healed, cared for, and helped. From the perspective of the staff person who caused such harm, to deadname and/or to misgender someone might seem like an inconsequential action, or even, in many cases (though not in this one), like an honest mistake. But it is not. To deadname or misgender someone is the equivalent of saying, "I don't recognize you for who you are; I don't accept your identity; I don't see you as worthy of respect or dignity; I don't see you as a human being." For anyone, this is harmful. But this is even more harmful for someone who has struggled to present as the gender with which they identify and who faces a continual threat of discrimination.

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However, it must be underscored that in Jasper's case, the deadnaming and misgendering he experienced, in addition to being publicly outed as transgender, was not an honest mistake. In fact, this administrative assistant intentionally called Jasper by his birth name, even though there was a note in his file specifically stating that Jasper was to be called "Jasper" and that he uses male pronouns. The person who deadnamed, misgendered, outed, and then lied to Jasper did so intentionally and was motivated by implicit or explicit transphobia and a refusal to recognize transgender people as people. This is a common tactic used to express disapproval of trans folks. Every incident of this kind confirms the threat that they face and also reduces their access to future medical (and other) social services for fear of this happening again.[12]

In addition to the personal dimension of the harm, there is the public dimension: Jasper was outed in public in front of a room full of strangers. This is not just an issue of language (though language itself is substantial and important). It could also be a matter of life and death. Trans folks are commonly assaulted and killed simply for being trans. Gender status is often not something that transgender individuals share with anyone, in particular with strangers. But even if they do share this information, it ought to be their choice. To be outed in public is a violation, an assault. And one that could cost someone their life.

Though from the perspective of the administrative assistant, such an interaction might not even register as problematic or blameworthy, let alone as harmful, it is quite the opposite to the one experiencing it. Nedra, a twenty-two-year-old genderqueer participant, noted that they do not visit any doctors for precisely this reason. For them, the fear, anxiety, and threat of being outed in public are simply not worth it. Jyme, a thirty-three-year-old transman, noted: "I've seen people in the waiting room be outed in front of other patients. Here it gets really confusing and people are really upset.... I do wish that the front desk would at least understand what I was there for, so that it wouldn't be 'yes, Ma'am' or 'can we help you, Ma'am' all the time."

Administrative assistants and staff are part of the medical world; in fact, they are often gatekeepers in the sense that they are the people with whom one must first speak to make an appointment; they are the people with whom one must first engage to see a doctor; they are the first people one encounters when one enters the doctor's office. Yet, what was remarkable to me in seeking to learn more about the health and health care of trans and gender nonbinary folks was that so much of the harm that happens in medical settings happens before patients even enter the examination room, before they even see a doctor or a nurse. This is a medical problem, but it is also a social problem: one that must be confronted and resolved. This is a problem that *can* be confronted and resolved, but according to one trans advocate, our training methods must change. Gabrielle Bouchard (2018), the first transgender president of the Fédération DES femmes du Québec (2010 [Quebec Women's Federation]), notes that most training on transgender issues in health care is

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aimed at doctors, nurses, and nurse practitioners. This is because it's easier to implement and develop such training in medical schools, nursing schools, and other accredited institutional settings. But staff are a part of a different structure, and it's harder to find accredited settings where they can be trained and held to professional, uniform, high quality standards of care (if such settings exist at all). As Bouchard (2018) notes, "Doctors and nurses can get training and that's all good but their efforts might all be for nothing if the staff they rely on to bring people to them are shutting the door to trans folks through transphobic gatekeeping."

Health care teams must not only better educate themselves on issues of transgender and gender nonbinary health, but must also better educate their staffs about the serious and enduring harms of what may seem, to those of us who are not transgender or nonbinary, an inconsequential action or mistake and what is often (though not in Jasper's case) an unintentional one. Such unintended actions come with dire consequences. As a result, people are choosing to forego health care and to jeopardize their health to avoid being deadnamed, misgendered, and outed. We must do better.

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NOTES

1. For a fascinating, detailed discussion of the myriad problems of obtaining such information, see Practical Androgyny: The Practicalities of Defying Binary Gender Classification (2014). Though the context is the United Kingdom, many of the points relate to the United States and Canada. Also see Chalabai 2014.
2. Specifically, they note that

   > striking gaps remain in our knowledge of GNC [gender nonconforming] people's utilization of health care services and physical health outcomes, longitudinal models of GNC people's health and the impact of gender-affirming services on their health, protective and supportive factors, and how each of these interacts with additional aspects of identity (e.g., race, culture, sex). (Eckstrand et al. 2016, 1110)

3. Trans PULSE (n.d.) was a community-based research project in Ontario, Canada, that collected qualitative and quantitative data from focus groups with eighty-five trans community members with the purpose of trying to understand how social exclusion impacts the health of trans people (Bauer et al. 2009).

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4. Race indeed amplifies the barriers and discrimination that trans folks experience. For example, fatal violence disproportionately affects transgender women of color. The intersections of racism, sexism, homophobia, and transphobia conspire to prevent them from obtaining employment, housing, health care, and other necessities. All of these barriers make transgender women of color a most vulnerable group (Human Rights Campaign, 2017).
5. The lack of insurance coverage for certain procedures and treatments for trans folks is an institutional and social problem that often causes medical problems (due to people not being able to afford and, therefore, not getting the care that they need, care that would be covered for cisgender people who need the same kinds of care and procedures). I'd like to thank Ive Simpson for emphasizing this point.
6. For a helpful discussion of binding and its dangers and the first medical study to examine this issue, see Tsjeng 2016. Also see Peitzmeier et al. 2017.
7. It should be noted that this struggle with one's identity is a result of a normalized social standard and conceptualization of bodies and of gender. I'd like to thank Ive Simpson for our discussion of this point.
8. One exception to this trend is the University of Louisville's *eQuality* (n.d.). This multi-year, national, pilot project was launched in 2015 and aims to implement a comprehensive medical school curriculum that requires students to learn, practice, and demonstrate mastery of skills, knowledge, and attitudes required for excellent care of patients who are lesbian, gay, bisexual, transgender (LGBT), gender nonconforming individuals, and persons affected by differences of sex development (DSD).
9. To "deadname" means to use a transgender person's birth name and not the name that they actually use; to "misgender" or "mispronoun" means to use incorrect pronouns to refer to a transgender or gender nonbinary individual (that is, pronouns that correspond to the sex they were assigned at birth and not the sex or gender with which they identify); to "out" someone means to expose their gender identity without their permission.
10. The names of all participants from the focus groups used in this commentary are pseudonyms they provided.
11. "Gaslighting," a term that originated in *Gas Light*, a 1938 British play by Patrick Hamilton—Alfred Hitchcock's movie version was released in 1944—refers to listeners not believing and/or expressing doubt about a speaker's testimony. Gaslighting is subtle and often, though not always, unintentional. Raising doubts about the speaker's credibility can result in their questioning their own knowledge. Such doubts both directly and indirectly harm the speaker and constitute an epistemic wrong, namely, a wrong with regards to one's capacity as a knower. For an excellent discussion of gaslighting, see McKinnon 2017.
12. I'd like to thank Gabrielle Bouchard for her insight on this point.

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